American Academy of Pediatrics
DEDICATED TO THE HEALTH OF ALL CHILDREN™



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U.S. Department of State
CA/OCS/PRI
Adoption Regulations Docket Room
SA-29, 2201 C Street NW
Washington, DC 20520

**RE: State/AR-01/98**

To Whom It May Concern:

On behalf of the 57,000 members of the American Academy of Pediatrics (Academy), I am pleased to offer the following comments on the proposed regulations to implement the 1993 Hague Convention on Protection of Children and Cooperation in Respect of the Intercountry Adoption and the Intercountry Adoption Act of 2000 (Docket number State/AR-01/96). The Academy recognizes that implementation of the Intercountry Adoption Act of 2000 is a major step in reformation of intercountry adoption proceedings in this country. We feel that above all else, children's rights must be protected during this process, and this is what motivates us to provide comments to the Department of State.

The American Academy of Pediatrics is comprised of primary care pediatricians, pediatric medical subspecialists, and pediatric surgical specialists who are dedicated to the health, safety and well being of infants, children, adolescents and young adults. For many decades, the Academy's work has included efforts concerning adoption and dependent care. As pediatricians, we have an important role in assisting adoptive families in the various challenges they may face with respect to adoption. Moreover, we are uniquely qualified to address the various health and mental health needs of adoptive children and their families.

In addition to submitting the enclosed comments, the Academy requests that the US Department of State reissue the proposed regulations for public comment prior to finalization. Such a review is warranted given the potential impact of the regulations on children worldwide.

We are grateful to you for your consideration of our comments related to intercountry adoption. Please feel free to contact me or Molly Hicks (800-336-5475, mhicks@aap.org) if you have any questions or would like further information.

Sincerely,

Carden Johnston

Carden Johnston, MD, FAAP, President
American Academy of Pediatrics

Enclosure: Comments regarding Intercountry Adoption Act

Cc: Sarah Springer, MD, FAAP
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CJ/pl

**Sec. 96.41 Procedures for responding to complaints and improving service delivery.**

(a) The agency or person has written complaint policies and procedures that incorporate the standards in paragraphs (b) though (h) of this section and provides a copy of such policies and procedures, including contact information for the Complaint Registry, to client(s) at the time the adoption contract is signed.

(b) The agency or person permits any birth parent, prospective adoptive parent, or adoptee to lodge a complaint or appeal about any of the services or activities of the agency or person that he or she believes are inconsistent with the Convention, the IAA, or the regulations implementing the IAA.

**Sec. 96.42 Retention, preservation, and disclosure of adoption records**

a) … on the issue of preservation of records, the convention requires that a child's social and medical information be preserved, but it does not set forth a specific retention period.

The records – medical and adoption – should be permanently retained. This should not be burdensome with electronic records, and can be very valuable information to the adopted person over the course of his or her entire life, as well as values information for future generations of that person's family.

**Sec. 96.69 Filing of complaints against accredited agencies and approved persons.**

(a) Complaints against accredited agencies and approved persons may be made as follows:

(1) The complaint must first be filed with the agency or person

(2) If the agency or person against whom the complaint is being made is a supervised provider, the complaint must also be filed with the primary provider;

(3) If a complaint is filed with a supervised provider, the supervised provider must instruct the complainant to also file the complaint with the primary provider and must provide the complainant with the primary provider's contact information;

(4) If the complaint cannot be resolved through the complaint processes of the agency or person providing the services or the primary provider (if different), or if the complaint was resolved by an agreement to take action but the agency or person providing the service or the primary provider (if different) failed to take such action within thirty days of agreeing to do so, the complaint may then be filed with the Complaint Registry in accordance with Sec. 96.70, which will refer the complaint to the accrediting entity or other appropriate authority in accordance with Sec. 96.70(b).

(b) A Federal government body, including DHS, a public body, any law enforcement authority or licensing authority, or a foreign Central Authority may make complaints directly to the Complaint Registry or the accrediting entity overseeing the accredited agency or approved person. Federal government bodies, including DHS, may report complaints directly to the Secretary.

We would point out that the only mechanism for a health care provider, such as a pediatrician, or a non-governmental body such as the American Academy of Pediatrics, to complain about agency practices is, according to Section 96.69, directly to the agency. However, Section 96.41 b seems to limit the right to complain only to birthparents, adoptive parents and the adoptee.

An individual practitioner, such as a pediatrician, is in a unique position to see a pattern of practice that is not obvious to a single family. Because we see children adopted through many agencies and many children adopted through the same agency, we are likely to detect adoption practices that are inappropriate and, occasionally, even illegal. It is not likely that a pediatrician would make complaints about such practices to an agency directly for several reasons.

1) HIPPA regulations prohibit us from divulging information about patients in our care
2) The health care practitioner has no contract with the agency and thus would be considered low priority in complaint resolution
3) A health care practitioner would be hesitant to disrupt a collegial relationship with an agency.
4) Many complaints would be based on the comparison of one agency's practices with another and it would not be appropriate to give information about one agency to a second.
5) Some inappropriate practices might be recognized only through dialog with other professionals, such as pediatricians who are members of the Section on Adoption and Foster Care of the AAP. The Section or some other professional body might wish to make a complaint about a general aspect of an agency's practice without reference to a particular case.

Thus, it would seem most appropriate to allow individual health practitioners, such as pediatricians and mental health care providers, and non-governmental groups, such as the AAP, a mechanism to make complaints directly to the Complaint Registry.

**Sec. 96.49 Provision of medical and social information in incoming cases.**

(a) The agency or person provides a copy of the child's medical records to the prospective adoptive parent(s) at least two weeks before either the adoption or placement for adoption, or the date on which the prospective adoptive parent(s) travel to the other Convention country to complete all procedures in such country relating to the adoption or placement for adoption, whichever is earlier.

(b) To the fullest extent practicable, the agency or person provides the prospective adoptive parent(s) with a correct and complete English-language translation of the records and, where the medical records provided pursuant to paragraph (a) of this section are a summary or compilation of other medical records, the agency or person provides a copy of the original medical records used to create that summary or compilation if the original medical records are available.

In addition to the English version, the family should also be provided with a copy of the untranslated or original language reports and laboratory studies. All other records pertaining to the child that might contain medical, social or developmental information should be provided to the family in both the original language and translated versions. This could include such items as school work produced by the older child, documents or letters written by the birth family or others to, for or about the child and video interviews with the child.

Videotapes are frequently provided to families when the child is older or has special needs. Often the child is interviewed or asked to recite. Occasionally, discussions about the child by caregivers or physicians are held during the taping of the child. Such videotapes should be translated for parents as they may contain crucial additional information about the child's level of functioning. Families should receive a translated transcript, and the original videotape.

All medical records are inherently a summary, except for the actual working record, noting observations and laboratory results as they are collected. It would be unwieldy and impractical to provide a copy of the actual original medical record, given the typical volume of such records and the probable lack of photocopying facilities. A detailed summary of the medical record covering the topics outlined in section 96.49d 1-4 as provided by the orphanage director or physician or another physician as appointed by the Central Authority of the sending country should be accepted as a best substitute for the original record.

However, many medical records provided to parents are actually prepared by the agency or a representative of the agency based on an interview with orphanage personnel or following review of orphanage records. The orphanage director or physician often has neither reviewed nor signed such "records." A statement typically appended to such records reads, "The information set forth on this form accurately reflects the summary of information provided by the baby home director regarding the above named child." In such circumstances, the family often has no way of knowing who wrote the record nor how accurate or complete it might be.

Similarly, some agencies or facilitators bypass the orphanage director/physician completely by bringing in an outside physician to examine and write a medical report. In such cases, it is not always apparent to the family whether the physician actually knows the child, whether he/she was given access to the child's medical or social records and/or caregivers and whether the director had the opportunity to review the resulting report for accuracy.

In circumstances where the medical record is produced by **anyone other than the orphanage director or physician or a person designated by the Central Authority of the sending country**, the family should be given a copy of the original medical records and/or an explanation of the how the information contained in the report was obtained and verified, who collected the information, including that person's credentials and an indication of whether or not the orphanage director or physician has reviewed the report for accuracy.

(c) The agency or person provides the prospective adoptive parent(s) with an opportunity to arrange another translation of the records, including a translation into a language other than English, if needed.

(d) The agency or person itself uses reasonable efforts, or requires its supervised provider or agent in the child's country of origin who is responsible for obtaining medical information about the child on behalf of the agency or person to use reasonable efforts, to obtain available information, including in particular:

(1) The date that the Convention country or other child welfare authority assumed custody of the child and the child's condition at that time;

(2) History of any significant illnesses, hospitalizations, and changes in the child's condition since the Convention country or other child welfare authority assumed custody of the child;

(3) Growth data and developmental status at the time of the child's referral for adoption; and

(4) Specific information on the known health risks in the specific region or country where the child resides.

Numbers 1 through 4 above should not be construed as the outline for medical reports but should be the **minimum acceptable data** to be included in a medical report. All growth data, from birth to present (or from the time the child came into care, if the child was abandoned) should be provided, not just the data at the time of the placement, since we know that the child's pattern of growth over time is important in assessing how difficult or good life has been for the child. One point in time does not tell the whole picture.

(e) If the agency or person provides medical information to the prospective adoptive parent(s) from an examination by a physician or from an observation of the child by someone who is not a physician, the information includes:

(1) The name and credentials of the physician who performed the examination or the individual who observed the child;

(2) The date of the examination or observation;

(3) If the medical information includes references, descriptions, or observations made by any individual other than the physician who performed the examination or the individual who performed the observation, the identity of that individual, the individual's training, and information on whether the individual relied on objective data or subjective perceptions in drawing his or her conclusions;

(4) A review of hospitalizations, significant illnesses, and other significant medical events, and the reasons for them;

(5) Information about the full range of any tests performed on the child, including tests addressing known risk factors in the child's country of origin; and

(6) Current health information.

(f) The agency or person itself uses reasonable efforts, or requires its supervised provider or agent in the child's country of origin who is responsible for obtaining social information about the child on behalf of the agency or person to use reasonable efforts, to obtain available information, including in particular:

(1) Information about the child's history and cultural, racial, religious, ethnic, and linguistic background; and

(2) Information about all of the child's past and current placements prior to adoption, including information on who assumed custody and provided care for the child.

This should include any relevant social work or court reports relating to the child's movements before and within the child welfare system. Without these documents, typically included in the summary documents of court hearings, parents may have no way of discerning whether moves were due to issues pertaining to the child, to the parent or to other environmental or social issues such as war or natural disasters. So, for example, to state that, "The child came into care because the mother died " carries a very different meaning and suggests very different long-term health needs for the child than "the mother was an alcoholic or drug abuser", "she committed suicide" or "died of a chronic illness" versus "maternal death in an earthquake."

(g) Where any of the information listed in paragraphs (d) and (f) of this section cannot be obtained, the agency or person documents in the adoption record the efforts made to obtain the information and why it was not obtainable.

(h) Where available, the agency or person provides information for contacting the examining physician or the individual who made the observations to any physician engaged by the prospective adoptive parent(s), upon request.

(i) The agency or person ensures that videotapes and photographs of the child are identified by the date on which the videotape or photograph was recorded or taken.

(j) Neither the agency or person nor its agents withhold from or misrepresent to the prospective adoptive parent(s) any medical, social, or other pertinent information concerning the child.

(k) The agency or person does not withdraw a referral until the prospective adoptive parent(s) have had at least a week (unless extenuating circumstances involving the child's best interests require a more expedited decision) to consider the needs of the child and their ability to meet those needs, and to obtain physician review of medical information and other descriptive information, including videotapes of the child.

The referral to "extenuating circumstances involving the child's best interests" in Section 96.49 k should be more carefully defined. A child whose medical condition is so precarious that a week's delay in the decision to adopt will place the child's life in danger will likely not live through the entire adoption process which typically involves several weeks even under the best of circumstances. Parents who are considering such a child should certainly take more than a week to assess their ability to deal with a possibly terminally ill child.

Most likely, this phrase will be used to justify overnight or other very short decision deadlines that may have nothing to do with the health or the safety of the child. For example, currently, typical explanations given to parents for a shortened decision period are:

- "the judge will be going on vacation"
- "the courts will be closing for the holidays"
- "the orphanage will reserve this referral for us only for the next 48 hours"
- "other families are considering this child"
- "the country will meet its exit visa quota for children for the year in the next few days"
- "and if you do not make a decision now"
- "the child might never get adopted"
- "he will have to live until terrible orphanage circumstances for many more weeks or months"
- "you are the best family to meet his needs"

In other words, circumstances external to the child may be used to force parents into hasty or ill thought out decisions.

In addition, the section, nor any other part of the regulations do not address coercive practices used by agencies surrounding child referrals. For example, typical ploys are:

- "You may take all the time you like to consider this referral but we can keep this child on "exclusive hold" for you for only 48 hours unless you secure the referral with a deposit.". (often several thousand dollars, usually not refundable)
- "You may review the preliminary information for as long as you like but you cannot have the full medical and social record until we receive a deposit " (again, often several thousands of dollars, not refundable
- "You may come to our office to review the full information on this child but you may not have a copy until you have paid the full fee."